

Welcome to the New Hampshire Autism Spectrum Disorders Registry

What is the NH Registry for Autism Spectrum Disorders?

In response to concerns with the increasing incidence of Autism Spectrum Disorders (ASD), the New Hampshire Legislature, in early 2008, approved He-M 501, a rule establishing and implementing a state autism registry. Statutory authority had been granted in 2006, with the approval of RSA 171-A: 30,31.

The rule requires all health care and other providers who are qualified to make a diagnosis of autism spectrum disorder to record their findings when a new case of ASD is diagnosed in a New Hampshire resident.

The purpose of this registry is to improve current knowledge and understanding of ASD, and to allow the conducting of thorough and complete epidemiologic surveys of the disorder. The collected data can then be analyzed in order to facilitate planning for services for children and adults with ASD and their families.

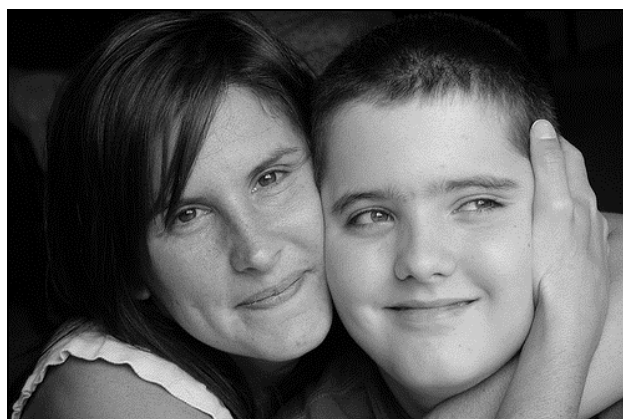
The New Hampshire Department of Health and Human Services, as a result of the bill, has established this online Autism Registry, in order for providers who diagnose new cases of autism to register their findings.

Why does NH have a registry for Autism Spectrum Disorders?

The impetus for the NH Registry originally came from the parents of children and young adults with ASD. Nationally -- and in NH -- it appears that the incidence of ASD is increasing. To improve knowledge, policy, practice and funding for ASD, the President of the Autism Society of New Hampshire crafted HB 1709 in collaboration with legislative sponsors.

Public agencies that provide services to children, teens and adults with ASD have been supportive of the NH Registry. Over time this database will be an invaluable tool in planning for the future needs of the ASD population. Because the NH Registry tracks

patterns in diagnostic assessment, it will also help public health officials to determine how well NH is doing in meeting the important goals of universal screening and early identification.



How common are Autism Spectrum Disorders?

Our understanding of the prevalence of ASD has evolved in recent years. For decades, autism was believed to occur in 4 to 5 per 10,000 children. In 2004, however, the Centers for Disease Control (CDC) partnered with the American Academy of Pediatrics to issue an Autism A.L.A.R.M. At that time, several studies indicated that prevalence rates were between 2 and 6 per 1000, or as high as 1 in 166 children.

Still more recently, the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network released data that found about 1 in 150 eight-year-old children in multiple areas of the United States had an ASD. Since the ADDM sites do not represent a nationally representative sample, the prevalence estimates should not be generalized to every community in the United States. Although accurate for the areas studied, rates may be higher or lower in other parts of the country.

Why is the NH Registry for Autism Spectrum Disorders important?



In recent years, there has been a great deal of public interest in the prevalence and incidence of ASD in the United States. Studies from California have suggested an increase of 273% from 1987 to 1998. This alarming news captured the attention of national media and the United States Congress. In 2001, Congressman Chris Smith (R-New Jersey) stated, "it is not an exaggeration to say that autism spectrum disorders may be the silent epidemic of our time....It is silent because there are currently no operational autism registries in the nation to tell us how many people actually have autism."

New Hampshire is the second state in the nation to establish a legislatively mandated, state-wide registry for ASD. A unique public health initiative, the NH Registry not only counts the number of new cases, but tracks the average age at which a definitive diagnosis is made. As other states follow with similar registry procedures, our combined efforts will help us understand more about the incidence of this challenging condition and how healthcare systems can best insure early and proper identification.

Who Reports to the NH Registry for Autism Spectrum Disorders?

Under He-M 501.02 (f), reporting is **mandatory** for "any physician, psychologist, or other licensed or certified health care provider who is qualified by training to make the diagnosis of ASD." This would include pediatricians, family physicians, psychiatrists, neurologists, licensed clinical psychologists, and social workers.

How does a clinician report a new diagnosis?

Clinicians must report using the electronic form on the NH ASD Registry web site (www.dhhs.state.nh.us/dhhs/bds)

If you are having trouble, contact Peggy Sue Greenwood at the New Hampshire Bureau of Developmental Services, Phone: 1-800-852-3345, Ext. 5034 (NH only) or (603) 271-5034, Fax: (603) 271-5166.

What Diagnoses are Included in the NH Registry for ASD?

For purposes of this registry, ASD is understood to include all five of the Pervasive Developmental Disorders: Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Asperger Syndrome, Retts Disorder, and Childhood Disintegrative Disorder (CDD). The *confirmed* diagnosis must be one of diagnoses, as per the *Diagnostic & Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR). Additional eligibility criteria apply:

- The NH Registry applies to all cases where a *definitive* diagnosis has been made. Suspicion of ASD and provisional diagnoses should not be reported.
- Diagnoses made prior to November 1, 2008 should *not* be reported.
- The person with the disorder must also live in the state of New Hampshire *at the time the diagnosis was made* to be considered for the NH Registry for ASD.
- The age of the individual and the presence of co-occurring conditions do *not* rule out the requirement to report the diagnosis.

THE NH REGISTRY FOR AUTISM SPECTRUM DISORDERS



Frequently Asked Questions For Families

Q. What is a registry?

- A.** A registry is an organized system for the collection, storage, retrieval, analysis, and dissemination of information on individuals who have a particular disease, a condition (e.g., a risk factor) that predisposes to the occurrence of a health-related event, or prior exposure to substances (or circumstances) known or suspected to cause adverse health effects. There are registries for many diseases, conditions and events (i.e. cancer, lead poisoning, influenza and birth defects including Down's syndrome). Without these registries, it would be impossible to understand the magnitude of a health problem and its impact on the public.

Additionally, information about when a diagnosis is made and by what type of medical professional can help policy makers understand the ways in which health systems are meeting important goals. For example, the age of diagnosis – and therefore the beginning of medically necessary treatment – is an important predictor of improved outcomes for children with ASD. Many professionals concerned with children's health in NH are not only interested in how many children are being diagnosed with ASD in our state, but at what age clinicians are typically making a confirmed diagnosis and whether there are regional or other differences in the average age of diagnosis.

Q. Why is there a need for a registry for Autism Spectrum Disorders?

- A.** There are a number of registries for ASD throughout the United States. Most are affiliated with an effort by the Centers for Disease Control to pinpoint the prevalence of ASD – that is, how common this health condition is in the general population – and whether this rate is increasing. These registries track the number of children diagnosed on the spectrum at the age of eight years within a specific area, usually several counties of a participating state.

New Hampshire has taken a slightly different approach. The NH Registry for ASD it is designed to answer three important questions:

- ❖ How many individuals are diagnosed each year in NH, regardless of age?
- ❖ At what age is the diagnosis typically made?
- ❖ And, when considering factors such as geographic region or the type of healthcare professional making the diagnosis, are there patterns that tell us more about how NH families access early developmental screening and evaluation.

While the NH Registry will contribute to our understanding of the prevalence of ASD in NH, the primary focus is on assessing whether early identification, screening, and ultimately diagnosis are taking place throughout NH. The information collected by the NH Registry will help policy makers to understand where there may be gaps in NH's system for screening and diagnosing children with apparent developmental delays that may be indicative of ASD.

Q. How common are Autism Spectrum Disorders?

We really do not know how many people in the United States, or in New Hampshire, have an autism spectrum disorder. In 2007, the Centers for Disease Control released data that found about 1 in 150 eight-year-old children in multiple areas of the United States had an ASD. Although accurate for the areas studied, more research is needed before this rate can be generalized to all parts of the US.

Q. How does the NH Registry help individuals with autism and their families?

- A.** The law that initiated the NH Registry for ASD was initiated by parents through the Autism Society of New Hampshire and other advocacy groups. Until recently, autism and related conditions were thought to be relatively rare. While promising initiatives like the Combating Autism Act of 2006 signal a recognition of this important issue at the federal level, funding for both research and treatment continue to lag behind that appropriated for many other, less common, conditions. Data from the NH Registry will have an impact on federal and state efforts regarding education in public schools, developmental services, community mental health, vocational supports and even insurance coverage.

Q. Are there other ways to find out how many people have autism and if it is increasing?

- A.** Yes, tracking (also called surveillance) programs can show how many people in a defined population and geographic area have a condition at a given time. For example, the CDC studied how many 3 to 10 year olds in metro Atlanta had autism in the calendar year 1996. They found that 34 in 10,000 had the disorder (significantly higher than the previously reported prevalence rate of 5 in 10,000). This alarming difference caught the attention of the U.S. Congress who charged the CDC with the task of providing collaborative agreements to other states to conduct similar monitoring systems.

However, the multiple sources monitoring system used in the CDC study is extremely labor intensive and can be costly over time. The same method must be implemented in subsequent years to look at any trends. For this reason, over time a registry for newly diagnosed cases is a more appropriate and cost effective means of building the necessary database to make well informed public health decisions at the state level.

Q. Will the name of the individual with an autism spectrum disorder appear in the registry?

- A. No. Names are not being collected.** There is no need to know the name of the individual in order to achieve the goals of the NH Registry. We do need to ensure that we do not enter a person twice (for example, if they receive a diagnosis by two or more diagnosticians, as families sometimes seek a second opinion). We are asking the healthcare professional reporting to use a designated standard method of coding each case that will allow the names to remain confidential.

Q. Who will have access to the information collected in the NH Registry for ASD and how will this information be used?

- A.** The total number of new cases of ASD diagnosed each year will be shared with a variety of

agencies that need this information for planning services and supports for individuals with ASD. The information will also be broken down (aggregated) by the age of diagnosis, the region in which the child lives, and the type of healthcare professional making the diagnosis. Among the agencies interested in the data collected by the NH Registry are the NH Bureau of Developmental Services, the Department of Education's Office of Special Education, the Bureau of Special Medical Service, and the Bureau of Behavioral Health. Annual results will also be published on this website.

It is important to know that *no individual data will ever be reported*. Any results reported will be across a group of individuals.

Q. Is this ASD registry legal? If an individual receives a diagnosis, does he/she have to be included in this registry?

- A.** Yes, the NH Registry for ASD is legal. Autism Spectrum Disorders are named a reportable condition under the New Hampshire Department of Health and Human Services, Administrative Rules Unit, He-M 501, adopted May 16, 2008. This addition to the rules was mandated by state law RSA 171-A:30, which was adopted by the NH legislature and signed into law by Governor John Lynch in 2006.

Will the families of those in the registry ever be contacted for more information or about participation in research because they are in the registry?

- A.** **No.** There would be no way to know who to contact. We do not collect name, address or phone number.

Q. How is an individual reported to the NH Registry?

- A.** If a medical doctor, licensed psychologist, or other healthcare provider makes a definitive diagnosis of autistic disorder (autism), pervasive developmental disorder not otherwise specified (PDD-NOS), Asperger Syndrome, Retts Syndrome or childhood disintegrative disorder, that diagnostician completes a short registry report form. The diagnostician indicates what the diagnosis is, the individual's date of birth, the date of the diagnosis, and the individual's NH town of residence.

Q. Are private practice physicians required to report new ASD cases?

- A.** Yes, in compliance with state law RSA 171-A:30 and state administrative rule He-M 501.

Q. If an individual receives an ASD diagnosis from a facility outside of New Hampshire, must that diagnosis be reported to the NH Registry for ASD?

- A.** **Yes.** Anyone who both resides in New Hampshire and receives a qualifying diagnosis after Nov. 1, 2008 should be reported to the NH Registry for ASD, regardless of where they received the diagnosis. For this reason, the NH Department of Health and Human Services is making every effort to reach out to diagnosticians in border states. Additionally, we would appreciate it if NH primary care physicians report cases where an out-of-state specialist has made the diagnosis. The registry is designed to eliminate duplicate entries, so primary care providers may register a patient without fear that this will corrupt the data.

Q. How can a family be sure that confidentiality will be protected?

- A.** Confidentiality is a *priority*. No names are collected and there is no information that would

enable anyone to trace a reported diagnosis to a specific individual. In addition, the database that stores the registry information is completely secure and requires a pass code for authorized personnel to enter it.

Q. Does the New Hampshire Registry for ASD comply with HIPAA?

A. Yes. Registries are considered *public health authorities* because their duties are mandated by state laws.

Under HIPAA, a “Public Health Authority” is defined as “an agency or authority of the United States, a State or territory, a political subdivision of a State or territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate.”⁽¹⁾

As a “Public Health Authority”, registries are “... authorized by law to collect or receive such information for the purposes of preventing or controlling disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions.” ⁽²⁾

(1) C.F.R. 164.501

(2) C.F.R. 164.512



Frequently Asked Questions For Diagnosticians

Q. Why was the NH Registry for ASD instituted?

- A.** The NH Registry for ASD was developed to help public policy makers in our state anticipate the needs of this apparently growing population, track the effect of improvement strategies aimed at lowering the average age of diagnosis, and better understand the magnitude of this public health issue.

Additionally, in May 2008, the NH Commission on Autism Spectrum Disorders released their **Findings and Recommendations**. The Commission outlined a number of ways in which the system of care for those with ASD must be improved. In order to successfully compete for federal and other funds to assist in implementing the Commission's State Plan, data collection on the scale implemented by the NH Registry is crucial.

Q. How much paperwork is involved in registering a new diagnosis?

Recognizing that diagnosticians must already balance many demands on their time, every effort has been made to keep the paperwork for the NH Registry for ASD to a minimum. This issue was discussed with the NH Medical Association and the NH State Board of Mental Health Practice, both of which reviewed the protocol and made a number of suggestions that were subsequently incorporated into the NH Registry. The Diagnostician Reporting Form can be completed online by support personnel and should take under five minutes to complete.¹

Q. If a child has failed a standard screening tool -- for example, the M-CHAT -- and been referred for further evaluation by a child development specialist, should I register that child?

- A. No.** A Diagnostician Reporting Form should only be filed when and if a *definitive* diagnosis has been made. The diagnostician making the determination – in this example, the specialist – is responsible for registering the child. However, it is important to know that the system is designed to identify duplicate registrations should two physicians file Diagnostician Reporting Forms.

Q. I have referred a child to an out-of-state specialist for further evaluation. If this specialist finds that my patient has an autism spectrum disorder, who files the diagnostician reporting form?

- A.** This is a situation where there is likely to be some confusion. As the primary care provider, you have two choices: You may provide a brochure and form to the out-of-state specialist as part of your referral, asking him or her to register the case if a definitive diagnosis is made; or you may wait for the results of the evaluation and register the diagnosis yourself when you receive the

specialist's report. Again, it is important to know that the system is designed to identify duplicate registrations, so there is no harm in filing a Diagnostician Reporting Form even when you have asked an out-of-state colleague to do so as well.

Q. I have a new patient who was diagnosed with an autism spectrum disorder in their previous state of residence. Should I register this patient?

A. No. Only patients who live in NH at the time of diagnosis are to be registered.

Q. I am a licensed clinical psychologist and see many young adults in my NH practice. I have recently diagnosed a patient with Asperger Syndrome. He is 26 years old and has not been previously diagnosed with this condition. Am I required to register this diagnosis?

A. Yes. The NH Registry for ASD collects all new diagnoses, regardless of the age of the patient, provided the individual is a NH resident at the time the diagnosis was made.

Q. Is the NH Registry for ASD affiliated with any CDC monitoring project?

A. No. The NH Registry is not a participant in current CDC monitoring projects, nor is it funded by the CDC. The goals of the NH Registry are more extensive than current CDC projects, which are primarily aimed at tracking the prevalence of ASD over time. While the NH Registry will contribute to our understanding of the prevalence of ASD in NH, it is also designed to identify and follow patterns in the average age of diagnosis, regional access to diagnostic evaluation, and the types of healthcare professionals making diagnoses in NH.

Q. How is the NH Registry different from the CDC's ADDM Network?

A. The Autism and Developmental Disabilities (ADDM) Network is a multi-site monitoring project sponsored by the CDC. Currently, 17 states participate in the ADDM network. New Hampshire is not among them. ADDM participants register children with ASD -- and in some cases other developmental disabilities -- at the age of eight years. The recommended protocol for the ADDM Network is more detailed than the NH Registry for ASD. Because protecting the privacy of NH citizens was a high priority, the clinicians and family members that developed the NH Diagnostician Form chose not to use the ADDM Network protocol.

Q. What are the implications under HIIPPA of sharing health-related information with the NH Registry?

A. HIPAA does not obstruct any state law that supports or mandates the reporting of diseases or injury for public health purposes. A physician, psychologist, or health care provider who gives information to the Department of Health and Human Services shall not be deemed to be, or held liable for, divulging confidential information. Moreover, the information shared does not include the name of the patient or other details that could identify the individual.

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New Hampshire Resources for the Developmental Evaluation of Children

Bureau of Special Medical Services
www.dhhs.state.nh.us/DHHS/SPECIALMEDSRVCS

Child Development Clinics in NH

- ❖ CHaD Child Development Program
Consultation Service, Lebanon, NH
www.dhmc.org
- ❖ Child Health Services, Manchester, NH
www.childhealthservices.org
- ❖ Laconia - Lakes Region Child Development Clinic
www.dknetdesign.com/lrecfr/agencylist.asp?servicetype=Child%20Development%20Clinics
- ❖ Lancaster - North Country Child Development Clinic
- ❖ Seacoast Child Development Clinic
www.seacoastclinic.unh.edu



Information about Early Screening and Child Development

Autism Speaks, ASD Video Glossary
www.autismspeaks.org/video/glossary.php

Bright Futures for Families
www.brightfuturesforfamilies.org/home

CDC Autism Information Center
www.cdc.gov/ncbddd/autism/

CDC Learn the Signs / Act Early
www.cdc.gov/ncbddd/autism/actearly/

CDC Child Development
www.cdc.gov/ncbddd/child/devtool/

First Signs, including “Red Flags for Autism” and the ASD Video Glossary
www.firstsigns.org

National Institute of Child Health and Human Development
www.nichd.nih.gov/publications/pubs/upload/autism_overview_2005.pdf

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Resources for Healthcare Professionals

American Academy of Pediatrics Clinical Report, “Identification and Evaluation of Children with Autism Spectrum Disorders,” Johnson, et. al. (2007).
aappolicy.aappublications.org/cgi/content/full/pediatrics;120/5/1183

American Academy of Pediatrics Clinical Report, “Management of Children with Autism Spectrum Disorders,” Meyers, et. al. (2007)
aappolicy.aappublications.org/cgi/content/full/pediatrics;120/5/1162

American Academy of Pediatrics, table comparing assessment tools –
www.medicalhomeinfo.org/screening/DPIP/screeningtoolgrid.pdf

Compendium of Screening Tools for Early Childhood Social-Emotional Development
www.cimh.org/downloads/IPFMH_Screeningtools.pdf

Medical Home Service System Guidelines for Autism Spectrum Disorders
[/www.waisman.wisc.edu/nmhai/](http://www.waisman.wisc.edu/nmhai/)

M-CHAT, Modified Checklist for Autism in Toddlers – Abstract pdf

M-CHAT Questionnaire and Scoring – pdf

National Academy for State Health Policy, Assuring Better Child Health and Development Resource Center (ABCD) www.abcdresources.org

University of Michigan Autism and Communication Disorder’s Center – for information regarding the ADOS (Autism Diagnostic Observation Schedule) and the ADI-R (Autism Diagnostic Interview-Revised (ADI-R) www.umaccweb.com/diagnostic_tools/index.html